Mobilizing Linguistic Resources for Diabetes Management in Latino Families

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Abstract:

Hispanics are at a greater risk for diabetes type 2 than whites. Research has been conducted on health outcomes based on family dynamics. However, a limited body of research exists on the patient's and family's perceptions of the challenges in managing diabetes type 2, specifically, examining the role of familismo on the Hispanic family's experience. In this research project, I conducted interviews of four Spanish-speaking families in four cities across Ohio and performed a content analyses to analyze the common themes. Dietary modifications were the most drastic changes for both patient and family, although the families accepted the lifestyle behavior modifications to varying degrees. Patients who adopted significantly different diets than other family members felt more isolated.

Background:

People of Hispanic origin have a higher rate of diabetes than the non-Hispanic, white population within the United States. Hispanics have an elevated prevalence rate of 12.1% compared to 7.4% for non-Hispanic whites (National Diabetes Statistics Report 2017, 2018). In Ohio the rates of prevalence increase for both Hispanic and non-Hispanic white populations with 13.2% and 9.9%, respectively (Ohio Diabetes 2010 Fact Sheet, 2011). Hispanic populations, especially older Hispanics, have lower education attainment, which influences literacy rates, access to care, and economic status of the individuals (Rosal and colleagues, 2004). All of these factors can exaggerate the burden of diabetes on patients and their families.

The State of Ohio predominately identifies as white (83%) compared to the United States as a whole with 72% identifying as white. However, between 2000 and 2010 the Hispanic population increased by 63% in Ohio, the fastest growing minority group in the state. The largest

Hispanic group in Ohio is Mexican. Lucas, Franklin and Hamilton counties all have Hispanic populations over 21%, while Lorain County's Hispanic population is more than 13% (Charting the Changes Ohio Demographic Profile, 2011). Four interviews of Hispanic families were conducted in the following cities in each of those counties during March 2018: Toledo (Lucas County), Columbus (Franklin County), Cincinnati (Hamilton County), Lorain (Lorain County). Columbus had the largest population of 860,090, then Cincinnati with 298,800, Toledo with 278,508 and Lorain with 63,730 (QuickFacts, n.d.).

Within the Hispanic/Latino population, the Spanish language is entangled in the concept of immigration. Spanish-speaking persons are often multilingual, communicating in either Spanish or English. These multilingual interactions are influenced with cultural values such as familismo, i.e. emphasizing the needs of one's nuclear or extended family over one's personal needs. The association between immigration, language, and family affect the financial, educational, and health well-being of Hispanic families.

Literature Review:

Research has been conducted on the cultural value of familismo and its influence on the health of Hepatitis C patients. The article "Familismo- Influence on Hispanic Health Behaviors" by Davila and colleagues identifies two patterns in familismo. One recurring theme is family support and the other is family responsibility. Family support is the obligation of the family members to emotionally and physically support the ill family member. Family responsibility is the patient's view of familismo and how the patient must maintain his or her role in the family in order to support them, which could include scarifying his or her own well-being (Davila Reifsnider, and Pecina, 2015).

Further research from Fisher and colleagues investigated the relationship between family characteristics and health outcomes in regard to diabetes management. Family characteristics have been measured by an Organized Cohesiveness self-report scale created by Fisher, a Family Coherence scale developed by Ransom and colleagues, as well as two family emotion management scales because of the stress diabetes can put on a family. These results were compared to five different measures of health outcomes: biological, general health, diabetes quality of life, emotional tone, and behavioral. An additional layer to this research involved comparing Hispanic patients to European-American patients. The results indicated that family structure and organization is important for disease management in Hispanics compared to the family world view and family emotion of European-Americans. However, the research suggests that these findings may have more correlation with the socioeconomic status of the participants, with Hispanics having lower SES compared to their European-American counterparts. In addition, this research focused on the health outcomes of the patient, neglecting the patient's and the family's perspectives (Fisher and Colleagues, 2000).

The study "Perceptions of Barriers in Managing Diabetes" by Dr. Jie Hu and colleagues examined the patients' and family members' opinions of the barriers to accessing care and managing diabetes type 2. Focus group interviews of the patients and their family members were compared to the hemoglobin A1C levels, blood pressures, and body mass indexes (BMI) of the participants. The patients reported three common challenges: first, obtaining a diabetes diagnosis; second, managing diabetes; and third, the lack of family support or knowledge to handle diabetes. The family members shared two common themes: they were capable of providing the support, but they lacked knowledge of how to do so (Hu, Amirehsani, Wallace, and Letvak, 2013). Hu and colleague's study allowed for further investigation on the role of

children, the influence of gender and the selection of the support system, which Mobilizing Linguistic Resources for Diabetes Management in Latino Families study intends to focus on.

Methods:

A case study methodology was selected as the research design for this project because it enables a full examination of the complexity of the contextual elements of the familial and linguistic impacts on diabetic disease management. This method also had the flexibility to allow the patients and their family members to share their personal stories and experiences in managing diabetes.

Four families, in four different cities in Ohio, were interviewed. All families were pulled from the Patient-Centered-Outcome Research Institute's Engagement Project, Building Capacity for Patient-Centered Comparative Effectiveness Research on Language Access for Patients with Diabetes - Tier II participant pool. Families were contacted and asked if they would like to participate an hour-long interview to discuss their family's experience around diabetes type 2. Interviews consisted of the patient and at least one other family member that was directly affected by diabetes or played a significant role in supporting the patient. One family was a patient and her adult daughter, another family was the patient, his wife and son along with two grandchildren. The third family was a patient and her aunt. The last family was a patient and her two sons of twelve and four years old. Interviews were conducted at a local public library in an attempt to reduce access barriers. All families were given a $40 gift card to either Walmart or Kroger, depending on what store was closer to their location.

Family sizes varied from five members to two members. Ages of participants differed greatly as well, with one participant in his 70's and the other three between 30 and 45. One

patient was male and the other three females. A list of open ended questions was passed out to all participants at the group interview. Refer to the appendix for the list of questions and the translations asked in the interview. Each patient and family member were given an opportunity to address every question. Additional follow up questions were asked throughout the interview to clarify the patient's answers. Interviews were completed during March 2018 and performed by the same researcher. All interviews took place on a weekday afternoon or evening and were done within an hour.

Hand written notes were taken during the entirety of the interview. A content analysis was performed on the data collected from all four interviews. The researcher analyzed common themes that were predetermined as well additional patterns found post-interviews. Three main research questions were focused on: 1. How are messages deployed by bilingual children through language brokering, the interpretation and translation of a concept to a party from another culture and linguistic background (Dorner, Orellana, and Jiménez, 2008)? 2. What role does the gender of the caregiver with diabetes have on disease management? 3. What factors determine the selection of who is the primary support for a patient with diabetes? An additional theme was found throughout the course of all the interviews, which health lifestyles were adapted, to what level and by who in the family. Ensuring that language barriers were minimized, all communication, including the interview, was performed in Spanish. However, two of the families' children requested to have an English assent form and therefore, questions were asked in English for them.

Results:

The content analysis performed on the interview data indicates that none of the families

used their children for language brokers. Two of the four families had their children involved in the health of their parent, the patient. In these situations, the children acted as a patient advocate. The children would ensure the diagnosis, lifestyle changes and routine care was understood as well as carried out by the patient. Both of these families had adult children while the other two families had either younger children or the children were not in the area. Neither of the families with children present at the appointment had them translate; the reasons varied from not having knowledge of the medical terminology or the medical provider already spoke in Spanish. Two of the four patients used an in-person translator at the appointment, one used a translator over the phone and as mentioned, one provider spoke in Spanish. Three of the families received all the take home information in Spanish. The fourth had everything in English and would use an online translator to help decipher what was meant. This same patient was the only one who could not call her health clinic or provider for questions she had but relied on Google to answer any questions.

Looking at the gender of the patient and the effect on the caregiver, the sample size was too small to find any trend. One of the patients was male and three of the patients were females. However, the questions asked focused on the lifestyle changes necessary for a diabetes patient and the whether the family also adopted these. Two of the families had complete diet shifts that strictly adhered to the diabetic diet. One patient encouraged the other members of the family to adhere to the diet but received negative feedback from them. However, the patient indicated her family had begun to make small changes, like portion size. The last family changed the food available in the house to have less tempting options for the patient but the family as a whole continued to eat the original diet. Another lifestyle behavior change that was asked about in the interview was exercise habits. The families that changed their diet also added regular exercising

into their routine. Of those two families, one had the patient exercise regularly, while in the other family the patient and the pre-diabetic son exercised. The other two families said exercise was irregular. One patient mentioned the cold winter weather for why she did not walk outside but was hopeful with seasons changing she would be able to walk more. The last patient, who also did not exercise, explained that with her family commitments and work schedule, she did not have time to exercise.

The last question a content analysis was performed on was who the main support system for the patient. All of the patients mentioned a close family member as their main support system for managing diabetes type 2. Three of the patients stated that their spouse was the main supporter while the fourth patient relied on her adult daughter. However, two of the spouses were not at the interview so their opinion could not be gathered. The other two patients who mentioned their main support system, either their spouse or daughter had that person in attendance, and both of them agreed with the statement. Reasons for picking the particular person as their main support system varied. Some qualities shared were: they are positive, they are with me every day, they are my partner, and they are going through similar things.

Discussion:

When discussing diabetes management, the primary focus of each family was slightly different. The Lorain family focused on changing their eating habits, especially portion sizes, to prevent health complications of the patient's daughter from worsening. In Columbus, the entire family adopted healthier lifestyles to avoid costly doctor visits. The Toledo patient's care was less family focused because the family was geographically divided. Her husband and extended family lived in the United States and her children lived in Mexico. Although the patient's aunt

attended the interview with the patient, the aunt was not active in everyday diabetes management for the patient. The patient had to manage her diabetes more independently without the active support or participation of her family members. The Cincinnati family was significantly younger than the other families in this study. The nuclear family changed their habits because the mother had diabetes and her twelve-year-old son was pre-diabetic. Extended family members also had diabetes, but they did not change their lifestyles, so the focus of diabetes management was much more central to the immediate family.

These narratives are not different from the ones found in previous research. Conversations with the Lorain and Cincinnati families revealed the role of familismo in managing diabetes by prioritizing the children's health. The families adopted different methods to do this, one more drastic than the other, but both families were making significant efforts. The Columbus family's efforts to minimize costly doctor visits by controlling their lifestyle behaviors is indicative of many families' experiences of barriers to healthcare due to cost. Latinos are more likely to be unable to afford healthcare services when they need it compared to any other racial minority group (Feder, 2010). The value of familismo is seen in this family's unity in controlling the diabetes. Lastly, the family in Toledo saw familismo in the wider family structure by sharing recipes and motivating the patient, although geographic separation complicated the patient's experience.

The findings in this study are consistent with those in Dr. Hu's "Perception of Barriers in Managing Diabetes." Difficulties in complying with the necessary dietary restrictions was echoed in both studies. Specifically, for the patients who had to make dietary changes without family support and participation expressed similar feelings of isolation and stress that the patients in Dr. Hu's project voiced (Hu).

Conclusion:

Familismo was not portrayed consistently or in the same manner within the families interviewed for this study. There were multiple variables, such as age of the patient, gender of the patient, family dynamics, and health statuses of other family members, that greatly influenced the four narratives. Although similarities in familismo were evident, there was also significant differences between families.

Within the Spanish-speaking community, sharing food and meals is an important component of the familial relationship. Meals are a valuable time for families to come together and share cultural cuisine. If a member is unable to participate in this cultural practice, he or she can feel isolated from the rest of the family (Devine, 1999 and Kulkarni, 2004). In addition, having to prepare two separate meals (one the family prefers and culturally traditional and another that is compliant with diabetes management) is time consuming. Three of the patients in this study were the female heads of household and were tasked with meal preparation in the family's division of roles. Medical professionals should be aware of the family dietary practices to best help the patient achieve lifestyle changes that are most effective. Understanding the patient's role in the familial context will allow for realistic changes customized to the individual's situation.

Research Limitations and Future Research:

This project served as an investigation into the potential role familismo on diabetes type 2 management. However, the sample size was very small with only four families being included in the analysis, so drawing conclusions from the findings should be done with caution. The second

research question was asked in a manner that did not allow the findings to be conclusive given the small sampling. Further research should investigate if a correlation of a patient's gender and the families' lifestyle changes exists. The patient's country of origin was not included in the project but should be considered in future work to determine patterns of specific ethnic groups. Lastly, this research examined the narrative surrounding diabetes, which has a genetic component, so family lifestyle changes and reaction to diabetes management may only exist for this type of condition. Future areas of research can investigate other disease types and the role of familismo.

Appendix:

1. ¿Quienes acompañan a la cita de doctor con el/la miembro/a de la familia con la diabetes?
    a. Who attends the doctor's appointments with the family member?

2. ¿Cuál tipo de servicio translación le usa en la cita, si usted lo usa?
    a. What kind of translation service is usually used, if one is used?

3. ¿Los niños acompañan a la cita del doctor y si es así los niños contribuir, observar o traducir?
    a. Do the children ever attend the doctor's appointments and if so do they contribute, observe or just attend?

4. ¿Después de llegar a casa, hay materiales de los médicos en inglés?
    a. After you come home are there materials from the doctors in English?

5. ¿Quiénes los traducen?
    a. Who translates these?

6. ¿Si tiene preguntas cuando está en su casa después una cita de doctor, a quién las usted pregunta?
    a. If you have questions when you get home after a doctor's appointment, whom do you ask?

7. ¿Cómo los hábitos alimenticios de la familia cambian después el diagnóstico?
    a. How has the family's eating habits changed since the diagnosis?

8. ¿Ha habido cambios en actividades físicos desde el diagnóstico?
    a. Have there been any physical activity changes since the diagnosis?

9. ¿El paciente sólo cambió su estilo de vida o la familia también cambió?
    a. Did only the patient change his/her lifestyle or has family changed too?

10. ¿Quién es el sistema de apoya que asiste en la gestión de la diabetes?
    a. Who is your support system to help you manage diabetes?

11. ¿Por qué los escogió?
    a. Why did you pick them?

12. ¿El sistema apoya tiene cualidades comunes?
    a. Do the people in your support system have common qualities?

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